Genetic Services

What is the service?

Publicly funded genetic services in Washington include support for genetic counseling services at nine of the 16 regional genetics clinics, the Regional Laboratory for the Diagnosis of Inborn Errors of Metabolism at Children's Hospital and Regional Medical Center (CHRMC), the Phenylketonuria (PKU) Clinic at University of Washington (UW), cytogenetics [1] testing for eligible patients, and prenatal diagnosis genetic counseling for Medicaid clients. In addition, all infants born in the state are screened for certain preventable disorders, many of which are genetic, through the Department of Health's statewide Newborn Screening Program. Affected infants are connected with specialty preventive care. Screening is funded by a fee charged to the parents through the birthing facility; clinical care receives funding through many sources, largely private insurance and Medicaid, with some support from Title V and screening fees.

- The Department of Health's Genetic Services Section (GSS) provides some of the funding to nine regional genetics clinics through the Maternal and Child Health Block Grant (Title V) and state general funds. Eight of the nine funded clinics provide prenatal genetic services, including diagnostic screening, evaluation, counseling, and/or treatment relating to the outcome of a pregnancy. All nine funded clinics provide clinical genetic services, including diagnostic screening, evaluation, treatment, and determination of carrier status and/or counseling delivered to a clinical genetic patient and/or members of the same family. All funded clinics also provide education about human genetics and access to genetic services to health professionals and the lay public in Washington State.
- Funding for the CHRMC laboratory helps support diagnosis of inborn errors of metabolism and provides diagnostic confirmation for several conditions identified through newborn screening.
- Title V, state, and local funds support the UW PKU Clinic, which provides diagnosis, assessment, genetic counseling, and consultation for ongoing dietary management and health supervision, as well as evaluation of treatment outcomes to all children with PKU and their families.
- GSS maintains an interagency agreement with Health Recovery Services Administration (formerly Medical Assistance Administration) to provide required matching state funds for the reimbursement of prenatal genetic counseling services for Medicaid clients.
- Individuals, including non-citizen immigrants, can receive financial assistance from GSS for cytogenetics testing based on a sliding scale.
- In accordance with state law, the Department of Health Office of Newborn Screening conducts statewide screening of all newborns for nine congenital disorders.
- Websites:
    - Genetic Services Section http://www.doh.wa.gov/cfh/mch/Genetics/Regional_Genetics_Clinics.htm
    - Newborn Screening http://www.doh.wa.gov/nbs

[1] Cytogenetics is the study of normal and abnormal chromosomes.

How/where is the service provided?

- In Washington State, Title V provides funding to the following genetics clinics: Blue Mountain Genetics Clinic in Walla Walla; CHRMC (lab and clinic) in Seattle (also serving a clinic in Bellingham); Inland Northwest Genetics Clinic in Spokane, Mary Bridge Children's Health Center in Tacoma, UW Medical Genetics Clinic in Seattle (also serving a clinic in Everett), UW PKU Clinic in Seattle, and Yakima Valley Memorial Hospital in Yakima (also serving Central Washington Hospital in Wenatchee).
- In addition, genetic services can also be accessed at Swedish Hospital (Seattle), Madigan Hospital (Tacoma), Group Health Cooperative, Kadlec Hospital (Tri-Cities), Obstetrix (Auburn and Tacoma) and Evergreen Hospital.
- Newborn screening specimens are collected at hospitals and clinics. Specimens are sent to the Newborn Screening Program's laboratory in Shoreline, Washington.

Eligibility

- Regional Genetics Clinics receiving Title V and state funds must accept all referrals.
- Cytogenetics: Men and women who are not eligible for Medicaid or other financial assistance programs, with family incomes at or below 200% of the FPL, are eligible for financial assistance. Title V and DOH state funded cytogenetics services are charged on a sliding fee scale for clients with incomes between 100% and 200% FPL. Clients whose income is at or below 100% FPL receive services at no charge to the client.
- Prenatal genetic counseling is provided as fee-for-service for any pregnant woman and/or newborn covered by Medicaid, including Healthy Options through 90 days after birth when it is medically indicated.
- Newborn screening is required for all newborns by law. Parents can refuse on religious grounds only.

Who is receiving the Service?

Clients receiving prenatal and clinical genetic services in Washington at clinics receiving some public funding, 2004; cytogenetics tests supported in part by Title V funds, 2004.

	Prenatal[2]		**Clinical**[3]		**Cytogenetics**[4]	
	Number	**Percent**	**Number**	**Percent**		
Sex						
Female	670	100%	1861	55%	In 2004, GSS provided financial assistance for cytogenetic testing for 2 patients.	
Male	n/a	n/a	1501	44%		
Ambiguous	n/a	n/a	17	1%		
Total	670	100%	3379			

[2] Unduplicated clients served in 2004 at clinics receiving some funding from Title V, as reported in the Washington State Genetic Services Minimum Data Set, 2004.
[3] Unduplicated clients served in 2004 at clinics receiving some funding from Title V, as reported in the Washington State Genetic Services Minimum Data Set, 2004.
[4] Unduplicated clients who received financial assistance for cytogenetics in 2004, Washington State Genetic Services Section 10/05.

Age					
<17	19	3%	471	14%	
18-19	24	4%	1103	32%	
20-24	99	15%	536	16%	
25-34	182	27%	272	8%	
35+	342	51%	333	10%	
Unknown	4	n/a	664	20%	
Race					
White	447	67%	2136	63%	Not Available
White/ Hispanic	28	4%	51	1.5%	
Black	2	0%	64	2%	
Black/ Hispanic	0	0%	2	0%	
Asian/ Pacific Is.	16	2%	105	3%	
Native American	20	3%	42	1%	
Mexican	147	22%	151	4.5%	
Other	4	1%	25	1%	
Other/ Hispanic	1	0%	36	1%	
Unknown	5	1%	767	23%	
Total	**670**	**100%**	**3379**	**100%**	

- In 2004, 77,774 infants (or 99.6% of births reported to the Newborn Screening Program) were screened for the required congenital disorders (does not include births at military facilities).

Issues/Concerns

- Title V funded clinics are confronting the increased cost of genetic services, and the increasing numbers of uninsured individuals, in the face of potential budget cuts.
- The increasing identification of genetic disorders and emerging screening and diagnostic techniques will soon outstrip the state's capacity to ensure appropriate access to high quality, comprehensive clinical and laboratory genetic services.
- At both the state and national levels, Medicaid expenditures continue to grow despite current cost containment efforts. Continuing budget shortfalls and reductions in services consistent with available resources are predictable.